

LIVING WITH CHILDREN WITH AUTISTIC SPECTRUM DISORDER: UNVEILING THE MEANINGS OF THE BEING-THERE-MOTHER

CONVIVÊNCIA COM FILHOS COM TRANSTORNO DO ESPECTRO AUTISTA: DESVELANDO SENTIDOS DO SER-AÍ-MÃE

CONVIVIENDO CON NIÑOS CON TRASTORNO DEL ESPECTRO AUTISTA: DEVELANDO LOS SENTIDOS DEL SER/ESTAR-AHÍ-MADRE

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Objective: to unveil the human experiences of mothers who coexist with children affected by the autism spectrum disorder (ASD). **Method:** A qualitative research based on Heideggerian phenomenology, with data collected through a phenomenological interview among 14 women/mothers, from January to March 2016. **Results:** the mothers expressed that the coexistence led to learning, changes as human beings, and the search to know everything about autism; as well as not being able to work due to the care the child requires, feeling excluded and overloaded. **Conclusion:** the reach of the existential movement of the being-there-mother in the coexistence with the son affected by ASD allowed to understand changes, demands, and burdens on women who, inauthentically, were engaged in the routine of care of their children. Getting worried with the fact they should offer all they could, they felt distant from the care with themselves and from their social and family relations. Similarly, due to the fragility of their social support network, they became bio-psycho-social-spiritually vulnerable.

Descriptors: Autistic Disorder. Mother-Child Relations Nursing Care.

Objetivo: desvelar sentidos de mães na convivência com filhos acometidos pelo transtorno de espectro autista (TEA). *Método:* pesquisa qualitativa, ancorada na fenomenologia heideggeriana, com dados coletados por meio de entrevista fenomenológica com 14 mulheres/mães, entre janeiro e março de 2016. *Resultados:* as mães significaram que a convivência trazia aprendizado, mudanças como ser humano e busca por saber tudo a respeito de autismo;

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e não conseguir trabalhar, por ter de cuidar do filho, sentir-se excluída e sobrecarregada. Conclusão: o alcance do movimento existencial do ser-aí-mãe na convivência com o filho acometido pelo TEA permitiu compreender as mudanças, exigências e cobranças que cabiam à mulher que, de modo inautêntico, ocupava-se com a rotina de cuidados ao filho. Preocupando-se em oferecer o melhor de si, sentia-se distante do cuidado consigo e com suas relações sociais e familiares. Do mesmo modo, pela fragilidade da rede de apoio social, tornava-se vulnerável biopsicosocioespiritualmente.

Descritores: Transtorno Autístico. Relações Mãe-Filho. Cuidados de Enfermagem.

Objetivo: develar los sentidos de las madres que conviven con niños con trastorno del espectro autista (TEA). Método: investigación cualitativa, basada en la fenomenología Heideggeriana, con datos recolectados por medio de una entrevista fenomenológica entre 14 mujeres/madres, de enero a marzo de 2016. Resultados: Las madres significaron que la convivencia traía aprendizaje, cambios en los modos de cuidar del niño, sentimientos de exclusión y sobrecarga. Conclusión: el alcance del movimiento existencial del ser/estar-abí-madre en la convivencia con el hijo acometido por el TEA permitió comprender los cambios, exigencias y demandas sobre la mujer que, de manera inauténtica, se ocupaba con la rutina de cuidados a su hijo. Preocupándose en ofrecer lo mejor de sí, se sentía distante del cuidado de ella misma y de las relaciones sociales y familiares. De la misma manera, debido a la fragilidad de su red de apoyo social, se volvía biopsicosocioespiritualmente vulnerable.

Descriptores: Trastorno Autístico. Relaciones Madre-Hijo. Atención de Enfermería.

Introduction

The autism spectrum disorder (ASD) is a syndrome that interferes in the conditions of neurological development, manifesting itself in the first years of life through changes such as persistent, total or partial deficiency in communication or social interaction, restricted and/or repetitive behavioral patterns, and a high interest for objects or specific activities. The cognitive abilities of people with this disorder vary quite strongly, ranging from intellectual disability to capabilities above the average of the population without the disorder. The ASD is chronic, and the functional disabilities in adult life stem directly from the inefficiency of monitoring and of the multi-professional treatments received through life⁽¹⁾.

Although there is no consensus regarding the causal factors that culminate in the development of the disorder, worldwide researches indicated an increase in the prevalence and incidence of ASD in the last decades, and the ailment affected 1 every 59 children in 2018^(2,3). This data indicates how relevant it is to consider the family of these people, especially the mother figure, since caring is an action that is culturally delegated to women. In their daily lives, children, adolescents or adults with ASD require attention and specific

care from their mothers, who feel physically and emotionally overloaded⁽⁴⁾.

Mothers show that difficulties regarding the insertion of their children in the family, the school, and society, lead to sadness, mental exhaustion, distance from friends, family members, and to the lack of time to dedicate to themselves. In addition, there are evidences of dissatisfaction and stress resulting from the insufficiency of guidance regarding the disorder and of access to child treatments and therapies. Also, emotional and economic challenges emerge, making it so women are caring for themselves and for their children in a way that, often, is not efficient⁽⁵⁻⁷⁾.

It is worth to ponder about the programmatic vulnerability to which women are subjects, due to the fragility of their support network with regards to the duo mother/child^(5,8). A stable network, with well-established programs and health policies, is known to make viable the integral, longitudinal, and coordinated care advocated by the Unified Health System (SUS). For that to take place, it is necessary to improve the qualification of health professionals, focusing on bio-psycho-social-spiritual care for people affected by the disorder, covering many fields of knowledge that are involved in research and

care, so they can subsidize maternal guidance and capacitation⁽⁹⁻¹¹⁾.

From this perspective, Nursing stands out as a profession which has in its very essence the care for Beings in an autistic state, as well as their families. Since undergraduate course, nurses are encouraged and equipped to develop technical and humanistic competences, through conscious acts of care which include counseling, bonding, decision making capabilities, sensibility, and critical thought⁽¹²⁻¹³⁾.

With regards to the ASD, the nurse could collaborate to find a diagnoses through the observation of the behavior of the children in nursing consultations, domiciliary visits, and hospitalizations⁽¹⁴⁾. In addition, by listening and considering the perception of the family, they can exchange knowledge with regards to the disorder, the monitoring, and evaluate the degree to which the individuals involved understand the situation, in addition to offering support and care to the relatives, regarding the reality with which they are confronted⁽¹⁵⁾. However, with regards to the care for the mother in the position of main caretaker, it is relevant to advance the perspectives through which the women-mothers who co-experience ASD with their children are understood, making it possible to become a partner in the care and management of situations that go beyond a biomedical model^(12,16-17).

Therefore, considering the growing epidemiology of ASD and the importance that it shows when it comes to offering integral care to person, family, and collectivity, the aim of this article is unveiling the meanings found by mothers by living with children affected by the autism spectrum disorder.

Method

It is a qualitative research based on the Martin Heidegger phenomenology approach, which makes it possible to understand human essence in its existence, which is shown as possibilities of opening and movement⁽¹⁸⁾. The Consolidated Criteria for Reporting Qualitative

Research (COREQ) was used as a directive for the methodological description.

In order to achieve the objectives established, possible participants were reached-out at meetings organized by an independent group for relatives of people affected by the ASD, in a city at the Zona da Mata region in Minas Gerais. The inclusion criteria included: being a woman, older than 18 years of age, and being the mother of a child with a diagnostic of autism spectrum disorder; those whose emotional state would not let them express themselves were excluded.

Through intentional sampling and the presentation of the research proposal in one of the meetings of the group, the women/mothers there were invited to participate, and 14 of them agreed. The field research stage took place from January to March 2016, through phenomenological interviews⁽¹⁹⁾, 10 of which were carried out at the woman's home and 4 in a public place, according to the preferences of the participants. It should be mentioned that the public place in question was an area near the group's headquarters, to which women take their children for monitoring. In all interviews, the researchers sought to prepare the place, to offer an environment that was calm and adequate enough to make it possible to carry out genuine phenomenological encounters, with privacy for the testimonies to take place, after the Free and Informed Consent Form was signed.

The interviews were recorded in audio and lasted for a mean of 20 minutes. To guarantee anonymity, the participants were identified by the letter T followed by a number corresponding to the order of the interview (T1, T2, T3, ..., T14).

The data collection instruments used were the interview, made up of questions regarding the historiography of participants (marital status, number of children, number of children with ASD, day of the birth and of the diagnostic of the children with ASD, religion, educational level, and profession) and of the guiding question of the interview (How, for you, is daily life with your child's diagnostic of autism?), in addition to a field journal that allowed for a record of the non-verbal communicational cues from the

participants, expressed through gestures and other manifestations.

After the transcription, the content of the interviews was carefully listened to and read. The analysis based on the Heideggerian theoretical framework started with the evidence of the essential structures and the elaboration of signification units: Coexistence brings learning, changes as a human beings, and attempts to learn all there is about autism; and not being able to work because they need to care for the child, feeling excluded and overloaded.

In the hermeneutic analytical movement, there was an attempt to understand the facts using the meanings expressed in the ontic sphere, or those of median or vague comprehension. Later, the meanings in the sphere of ontology, or interpretive comprehension, were unveiled.

The finishing of the data collection stage took place after an in-depth analysis of the texts that made up the interviews, in which no distinctions that implied the need for other testimonies were found. Additionally, this research considers that the phenomenon under study - mothers who live with children affected by the autism spectrum disorder - was achieved because there were sufficient significants that attended to the objective established.

The ethical aspects were considered, and all recommendations of Resolution n.466/12 of the National Council of Health were respected. The approval and permission by the Research Ethics Committee of the Universidade Federal de Juiz de Fora were granted under the Protocol 1.254.423 and CAAE 49453115.5.0000.5147.

Results

The mean age of the 14 participants was 39.9 years old. Regarding their marital status, 57.14% were married, 35.7% single, and 7.14% were divorced. The mean number of children per woman was 1.8 and 100% had only one child with ASD. The mean age of the child at the moment of the diagnostic was 2.6 years old. From the children affected by the disorder, 10 were male and 4 were female. Regarding the

educational level of the mother, 64.3% had complete high school, 7.1% had incomplete higher education, and 28.6% had complete higher education. Regarding their work, 7 declared to be housekeepers.

In “Coexistence brings learning, changes as human beings, and attempts to learn all there is about autism”, the experience of mothers with the diagnostic of autistic spectrum meant that they learned more than their children during the time they shared. In this learning process, they changed as human beings, started doing things that they could not before, and to wait the time the child needed, as the texts below express:

The time I spend with G. has made me learn [...] You learn that it had to be you. That I needed to polish myself as a human being [...] Even my tone of voice today, in conversations [...] is different. (T2).

After I had my child, I know what being a human means [...] I learn a lot from S., because I found that I have strength I didn't know I had! S. made me see I was not that failure [...] who was always crying, you know? (T13).

In the cause of autism, we should change the ways we act and think [...] today I feel very happy about the girl I have. We learn a lot with them. We have more to learn from them than they have from us. (T3).

We get used to it, learn to live together, we enter in their world and try to bring them to our world. She does not have any hearing problems, it's really only her speech. So, I learned to wait for her own time. (T8).

Every day is a learning experience. I say that I am happy, having an autistic child at home. It led me to do things I couldn't do before! After he entered the parents association, that's when I learned to live with him. (T10).

I started to live with her and to learn things with her too [...] That's because they show us a different world [...] different from the one we live in, with all the prejudice. (T4).

Mothers understood that they needed to research about some aspects of autism, and to participate in congresses and other events, so they could work with their children and help other children, as it denoted by the following texts:

I had to pay more attention in this aspect of my son's personality, in the things he was presenting, and I needed to take action about it and, ever since, I have been researching and going to many meetings, congresses, everything about autism. This has been very good. (T15).

I have learned that, in autism, with the amount of information and stimuli they receive, sometimes, they need some time to work, their time is different from others.

Sometimes, he needs to retreat in the process, because, for him, everything is a little slower. (T6).

I have never even heard the word autistic. So, I have started searching on the Internet, in books. I participated in a bunch of seminars [...] Now, I want to know any information about autism. (T9).

Many things even helped me in my profession [...] because there's a lot about speech therapy [...] I would apply that in my school and that also meant I could help the children. (T7).

With regards to “Not being able to work because they need to care for the child, feeling excluded and overloaded”, the mothers signified that living with the child makes it more difficult to have a job, to be invited to family and school events, in addition to generating feelings of lack of support, as the following fragments show:

[...] I have tried a lot of things to have an income, but sometimes it's difficult to accommodate the time. (T12).

I stopped working, I stopped doing everything I used to do so I could be with her. (T4).

The overload is very high, and I need, as the mother of an autistic child, to also undergo a psychological treatment, so I can deal with this situation [...] there are no professionals prepared to take care of the family with this syndrome, right? (T3).

I used to say I have no life anymore [...] I was working at full force, I was taking care of the children and working [...] than, at this rate, I got crazy [...] I wasn't well accepted you know? Well it was all very painful for me [...] I felt very lonely and sometimes even my friends left me behind [...] I have asked for help many times, I screamed: “help, help everyone, I'm here!” (T6).

People don't invite you to parties, they don't invite you anywhere because there are going to be rants there [...] even the family excludes you a lot, because, if you go their houses, you're a nuisance (T10).

Hermeneutics allowed to unveil the existential movement of the being-there-mother who is living with a child affected by ASD, which showed itself to be inauthentic, as it described changes dictated by the fact that is the disorder. This existential movement was unveiled during the work represented by the healthcare required by the disorder, as well as in the concern characterized as solicitude, regarding the child, and the concern characterized as deficiency, regarding friends and family.

Discussion

Living with the child affected by the ASD in this study brought, for the being-there-mother,

learning opportunities and discoveries to which they were led by the limits and possibilities of the disorder, generating internal and external transformations. When, as a human, the mother gives meaning to a change, she does not do so based on herself, but on the conditions imposed upon her by the ASD, which it characterizes the inauthenticity⁽¹⁸⁾.

Similarly, mothers have reported to deal well with the new way they live with regards to the ASD diagnostic of their children, despite signaling that they understood their lives as different from normal. That is because, with the new routine of care, in addition to performing the typical tasks of motherhood, they needed to dedicate more time to the daily care routine and to the therapies to which their children were submitted⁽⁶⁾. At the moment of diagnostic, mothers and fathers could assimilate and accept the information equally, but from that point on, the quality of life of the mother was low⁽²⁰⁾, since the difficulties regarding responsibility overload and care affected them more strongly⁽¹⁰⁾.

By unveiling themselves through occupying themselves and through the concern that is characterized as solicitude with regards to the child, the mothers of this study described they should

dedicate themselves entirely to their children, they are seeking to learn and getting more information about the ASD using many different means, among which the presence of a health professional who would embrace their needs and guide them about care was not. The relatives also distanced themselves, which affected the social and emotional dimensions of the participants.

The mother, as the main caretaker of the child with ASD, maintains and adapts her role as a wife, a family member, a professional and a woman, dealing with the emotional consequences of herself and of her family members⁽⁶⁾. The long-term nature of this parenting-related stress determines significant short and long-term effects on mental, psychological, and physical health, meaning it can significantly affect the mothers' work, domestic life, selfcare, and relationship with other relatives⁽²¹⁾.

The social support is a factor that has a positive effect for the families of people with ASD, as it helps reducing stress. However, evidences find that there is insufficient social support⁽²⁰⁾. Mothers noticed that they started being excluded from meetings, dates and conversations, which, as they have often observed, it was not what happened for friends whose children had approximately the same age but did not have ASD. As they sought support from someone who could embrace them and their singularities, they would only find this support in other mothers who were in similar situations⁽⁶⁾ or in groups of parents in specialized institutions, which offered a space in which there was empathetic listening, exchange of affections, and professional support⁽²²⁾.

The meaning of the concern of the deficient kind indicates “[...] the being for another, against another, without others, the passing by one another without feeling touched by others”^(19:178). The absenteeism of family members and professionals was understood by mothers as a lack of embracing, which makes it possible to reflect on the absence of mobilization, mainly in the field of health - especially in nursing -, of humanistic and humanization principles, which involve active and qualified listening, responsibilities, and a commitment to the demands of another⁽²³⁾.

The invisibility of the nurse in the meanings shown by this study highlights the requirement for sensitization, mobilization, and professional training in the spaces of care for the health of mothers and other relatives that daily coexist with people with ASD. In this study, it can be noted that the healthcare network did not manage to attend to the principle of integral health, generating a social and programmatic vulnerability^(8,24).

The mothers have minimal access to services for their children, and nearly none for themselves, which may lead them to develop depression and anxiety. The prompt access to educational information, therapies, and guidance, becomes essential to maximize the maternal and family directives, in order to grant all the autonomy possible to the children with ASD

and psychosocially empower these women. As a health educator, the trained nurse can become a factor capable of changing the development of the mother-child relation, offering knowledge on the disorder and support and care to the mother in her family dynamics, aiming to offer an integral care to all members involved^(15-16,21).

Since this research was carried out using a phenomenological approach, it has, as a limitation, the fact that it was carried out within only one setting. However, due to the epistemological rigor adopted in the investigation, the results found highlight relevant aspects that should be considered in the clinical practice of nurses who work with the mothers and relatives of children with autism spectrum disorder.

Conclusion

The reach of the existential movement of the being-there-mother in the coexistence with the son affected by ASD allowed to understand changes, demands, and burdens on women who, inauthentically, were engaged in the routine of care of their children. Worried with the fact they should offer all they could, they felt distant from the care with themselves and from their social and family relations. Similarly, due to the fragility of their social support network, they became bio-psycho-social-spiritually vulnerable.

Regarding the invisibility of nursing professionals, among which is the nurse, there should be more opportunities to acquire knowledge and domain over aspects of the disorder that go beyond its biological aspect, potentially resulting in a better care to the mothers. The necessary effort to define and effectively apply public policies for women's health care, in a way that is articulated to their demands, is an ally in this process.

Finally, it should be highlighted that the Heideggerian phenomenology theoretical framework, as focused on Being, allows for and aids the understanding of the subjectivities that permeate the routine work in health, pointing towards directions that can enlighten new researches, increasing the knowledge about Nursing.

Collaborations:

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